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ABSTRACT

This paper discusses the design of a program by the Nashville (Tennessee) Center for Independent Living (CIL) to train consumers with disabilities in employing, training, supervising, and firing personal attendants. The program, supported by the Tennessee Developmental Disabilities (DD) Planning Council, provided an opportunity for program design and evaluation to begin together. The process began with an evaluability assessment, in which evaluators worked with the CIL project staff and the DD Council in a strategic planning process which helps ensure sound management of the new program, including the development of agreed-upon objectives and achievement measures that would make an independent evaluation of the project meaningful. One of the first accomplishments of the evaluation was that the program staff and the DD Council agreed that the program design should be shifted from training of both consumers and personal attendants to training of consumers and development of a guide to personal attendant services. Issues to be considered in provision of personal attendant services were identified, including personal security, personality, skills, and financing. Evaluators will also work with the CIL project staff and the DD Council to produce a working model of the service and detailed service definitions. The paper concludes that use of evaluability assessment can result in clarity of purpose, design of successful programs, and ability to demonstrate this success to policy makers. (JDD)

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EVALUATING THE FEASIBILITY OF A PERSONAL ATTENDANT TRAINING PROGRAM: HOW DO YOU DETERMINE WHETHER A CENTER OF INDEPENDENT LIVING HAS THE RESOURCES AND CAPABILITIES TO OFFER THIS TYPE OF PROGRAM

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INTRODUCTION

In January, 1992, the Tennessee Developmental Disabilities Planning Council issued an RFP which included "a project to promote and strengthen independent living centers in Tennessee..." There followed a list of 14 specifications, including development of "a model personal assistance services resource program to include a referral pool of personal assistant candidates, training, and a manual for those who use personal assistants in employing, training, supervising and firing personal assistants." The specifications included participation in a program evaluation process selected by the DD Council.

A Center for Independent Living (CIL) is a place where people with disabilities may receive information and counseling which will allow them to live productively in community settings. A majority of the board and staff of a CIL are persons with disabilities. The services generally include information and referral, peer counseling, advocacy, and training in independent living skills. In addition, some centers provide employment counseling and housing location and counseling services.

In July, 1992, the DD Council awarded a grant to establish a Center for Independent Living in Nashville. The Council also contracted at that time with Richard Schmidt Associates in Bethesda, Maryland, to conduct an evaluation of the Nashville Center for Independent Living. This evaluation is being conducted in the ideal situation in which the evaluators participate in the earliest stages of the program development.

The evaluation design includes, initially, an evaluability assessment, a technique developed by Richard Schmidt and Joseph Wholey, and whose central purpose is to determine the extent of agreement among stakeholders on the program intent or design. The evaluability assessment of the Nashville Center for Independent Living, because it is carried out in the development stages of the project, assures that the program design and the evaluation design occur in a single integrated process. During the evaluability assessment, the evaluators are working with the CIL project staff and the DD Council in a strategic planning process which helps ensure sound management of the new program, including the development of agreed-upon objectives and achievement measures which will make an independent evaluation of the project more meaningful than most evaluations.

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One of the first accomplishments of the evaluation was that the program staff and the DD Council agreed that the program design should be shifted from a program that included training of both consumers and personal attendants to one that now focuses on training of consumers and development of a guide to personal attendant services. That design modification occurred during the exploration of the initial design parameters, in which it became clear that the level of resources available to the CIL at this stage of its existence would likely not permit development and implementation of such a broad program in this one area, given all of the other areas of activity required. In addition, a range of concerns surfaced about the training of personal attendants which require a re-examination of thinking about such training. These issues comprise one of the principal concerns of this paper.

Many of the issues in the area of services for persons with disabilities are relatively new because services have not developed as rapidly as the demands of a population which has (1) expanded enormously over the past 20 years, and (2) increased its power in many public arenas over the past five years.

The training of personal attendants was affected by two factors reflecting these changes. (1) In the past the population for whom personal attendants were available had less severe disabilities than many in the current population; and (2) funding was available for only certain categories of persons, for example, persons with mental retardation, or persons with mild disabilities for whom sheltered workshops were the option, or whose integration into the workplace was relatively easy.

In the absence of reliable sources of funding for the training of personal attendants, the focus was shifted to the individual with disabilities who wished to employ a personal attendant, and to assisting these individuals to train their own attendants, decreasing their vulnerability.

Personal assistance represents a form of service that, although such assistants have been employed by persons with disabilities for years, has become recognized particularly by persons with disabilities, but also by social service agencies, as a major part of independent living arrangements. The most important part of defining an approach to evaluating the training of personal attendants is the definition of the full requirements of the position.

ISSUES IN PERSONAL ATTENDANT SERVICES

1. Personal Security -- Perhaps the most fundamental issue for persons with disabilities who requires a personal attendant is personal safety. Finding people who are honest, emotionally stable, and physically able is an extremely important process. It seems clear that Individuals hired into these positions should be bonded to protect person with disabilities.

2. Personality -- Personal attendants provide varying kinds of care, much of which is highly personal. People providing such care need to be sensitive to the needs of others and capable of performing such personal care without intruding on the independence of person with disabilities beyond that necessary to perform the specific care.

3. Skills -- The single most complex issue facing the independent living movement is defining the skills needed by effective personal attendants. Unlike nurse assistants who are used so extensively in the long term and acute care industries, personal care attendants are not well organized in any sense. More importantly, their locus of use and their employers vary so widely that there has been no standardized employment base and thus no standardized skill development programs. Their services range from those that might be expected of a nurse aide to relatively modest cleaning and cooking services.[1] There are currently no certification or licensing requirements, no standardized training programs[2], and few formal processes by which such persons become screened for hiring purposes.

4. Financing -- A number of government social service programs provide funds for personal assistants, although the scope of coverage is extremely low when compared with the need. Most of these services are financed personally by the consumers. This approach has certain advantages and disadvantages. The main advantage is that the service can be tailored exactly to meet the needs of individual consumers, including individualized training by the consumer. The main disadvantage is that centralized approaches to recruiting, training, certification, etc. which might improve the standards by which such

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1 The tasks include: 1) personal maintenance and hygiene activities such as dressing, grooming, feeding, bathing, respiration, and toilet functions, including bowel, bladder, catheter and menstrual tasks; 2) mobility tasks such as getting into and out of bed, wheelchair or tub; 3) household maintenance tasks such as cleaning, shopping, meal preparation, laundering, and long-term heavy cleaning and repairs; 4) infant and child-related tasks such as bathing, diapering, and feeding; 5) cognitive or life management activities such as money-management, planning and decision-making; 6) security-related services such as daily monitoring by phone; and 7) communications services such as interpreting for people with hearing or speech disabilities or reading for people with visual disabilities. World Institute on Disability, Executive Summary of the National Survey of Attendant Services Programs in the United States, April 1987.

2 Training exists in many personal assistance programs, but, unlike the nurse aide program in which state certifying examinations are required by Federal regulations, the training has never become standardized or comprehensive on either a national or statewide basis. A considerable number of programs allow training by consumers, many of whom to provide all or part of the training themselves.

attendants operate, are made considerably more difficult. Self-financing has also produced a generally low wage system with high turnover.[3]

The CIL program in Nashville intends to develop a set of services associated with personal assistance, modeled after independent living standards. The program services are still under development, although candidate services include the following:

- Training of consumers in hiring, firing, and management of personal attendants, relying mainly on the experience of persons with disabilities who have learned over time how to function effectively as managers of personal attendants;
- Development of a reference guide to the effective use of personal attendants;
- Development of a data base on personal attendants that could be used by consumers seeking such services.

Under consideration, although now far down the list of priorities is a program to train personal attendants. In this area, it is much more likely that the Nashville CIL would develop a program in which training services could be made available by other institutions, community colleges for example, working with the community of consumers of such services.

The evaluation approach being applied to the training area will follow the general model being applied to the CIL as a whole. As mentioned above, the first step in this evaluation is an evaluability assessment, which has already had the result of re-defining the personal attendants training components. The central purpose of evaluability assessment is to increase the utility of subsequent evaluation studies, by aligning those studies with program reality, avoiding one of the more common evaluation flaws evaluating programs according to false notions of the program design invented by evaluators to cover the absence of agreed-upon program designs. In this case, because the evaluators will be dealing with a new program grant, agreement on the design should be much easier to achieve than in cases in which long entrenched programs are suddenly subjected to assessment from outside, only to discover that there is no agreement on the intent or design of the program.

During the evaluability assessment, the evaluators, in working with the CIL project staff and the DD Council in a strategic planning process for the CIL as a whole will produce working models of each of the CIL service areas. For example, an initial model of the CIL is illustrated in figure 1. That model illustrates the general logic of the program as it

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3 It is important to recognize that low wages and high turnover are characteristics shared by other equivalent personal services, e.g., nurse aides where minimum wage is common and turnover rates approach and often exceed 100%.

is currently designed. Note that at this early stage of the project, there remains a substantial amount of definition to be completed. In the area of personal attendant services, for example, the evaluators and the CIL staff members will engage in a preliminary design exercise aimed at exploring the needs and the capability of the CIL to satisfy those needs. Following the general logic of evaluability assessment, the Nashville CIL is developing its program design and its evaluation design as a single integrated process. During the initial stage of definition, the program design shifted from a program that included training of both consumers and personal attendants to one that now focuses on training of consumers and development of the guide to personal attendant services. That design modification occurred during the exploration of the initial design parameters, in which it became clear that the level of resources available to the CIL at this stage of its existence would likely not permit development and implementation of such a broad program in this one area, given all of the other areas of activity required.

The mission of the Nashville Center for Independent Living, developed during a two-day strategic planning session with the evaluators, is "To provide a central, consumer-controlled resource to enable people with disabilities to develop and achieve their individual visions of independent living with the participation of the community and its resources." This simple, focused statement provides a clear articulation of the values and goals of the Center. The impact of the evaluation and strategic planning process has, thus, been imbedded in the development of the program.

During the next stage of the evaluation, the CIL staff will work with the evaluators on more detailed definitions of CIL services. For each of the services, for example the personal attendant service, the CIL and the evaluators will work jointly to define:

- The specific purposes of each of the personal attendant services, e.g., the training of consumers.
- The underlying logic that links the provision of training to the needs of consumers.
- The most appropriate means of verifying that the services are being provided.
- The most appropriate means of measuring the success of the training. For example, consumer satisfaction is one form of measurement, but has only limited utility in aiding in the further refinement or modification of the training program. Other measures of utility will be employed, for example measures by which consumer capability changes can be assessed.
- The most efficient means of collecting data on performance over time. The best evaluation design cannot overwhelm the resources of the program being evaluated.

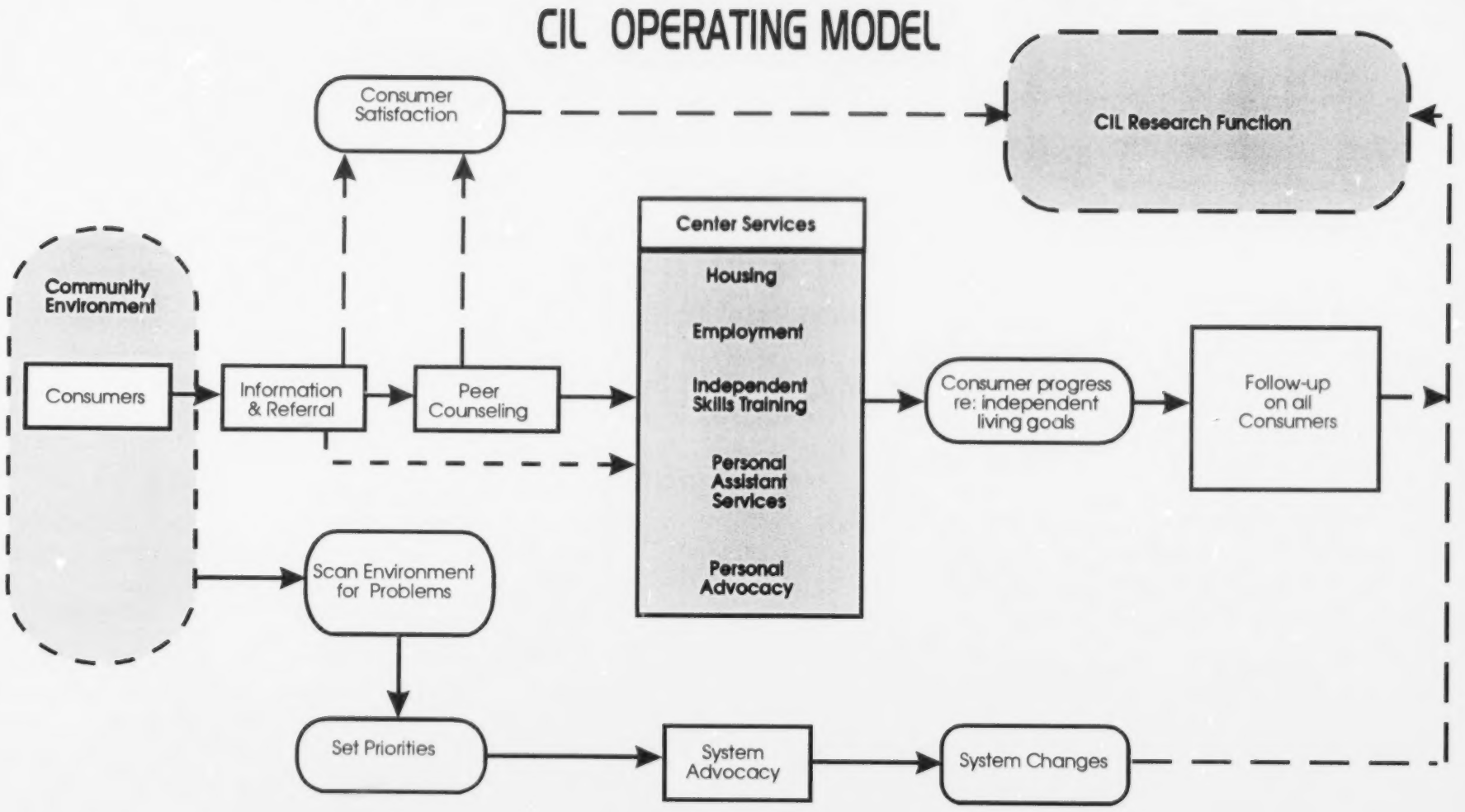
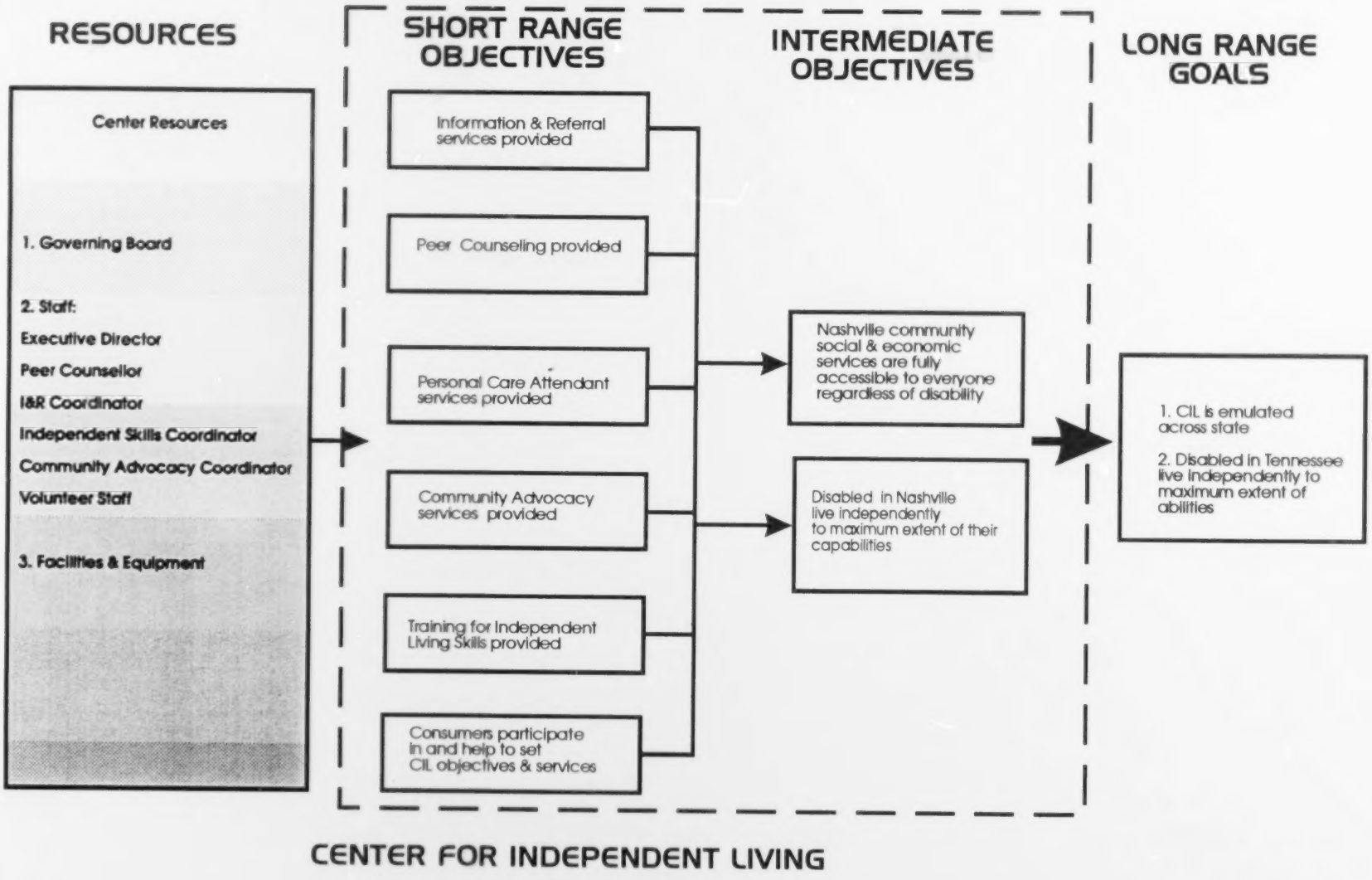
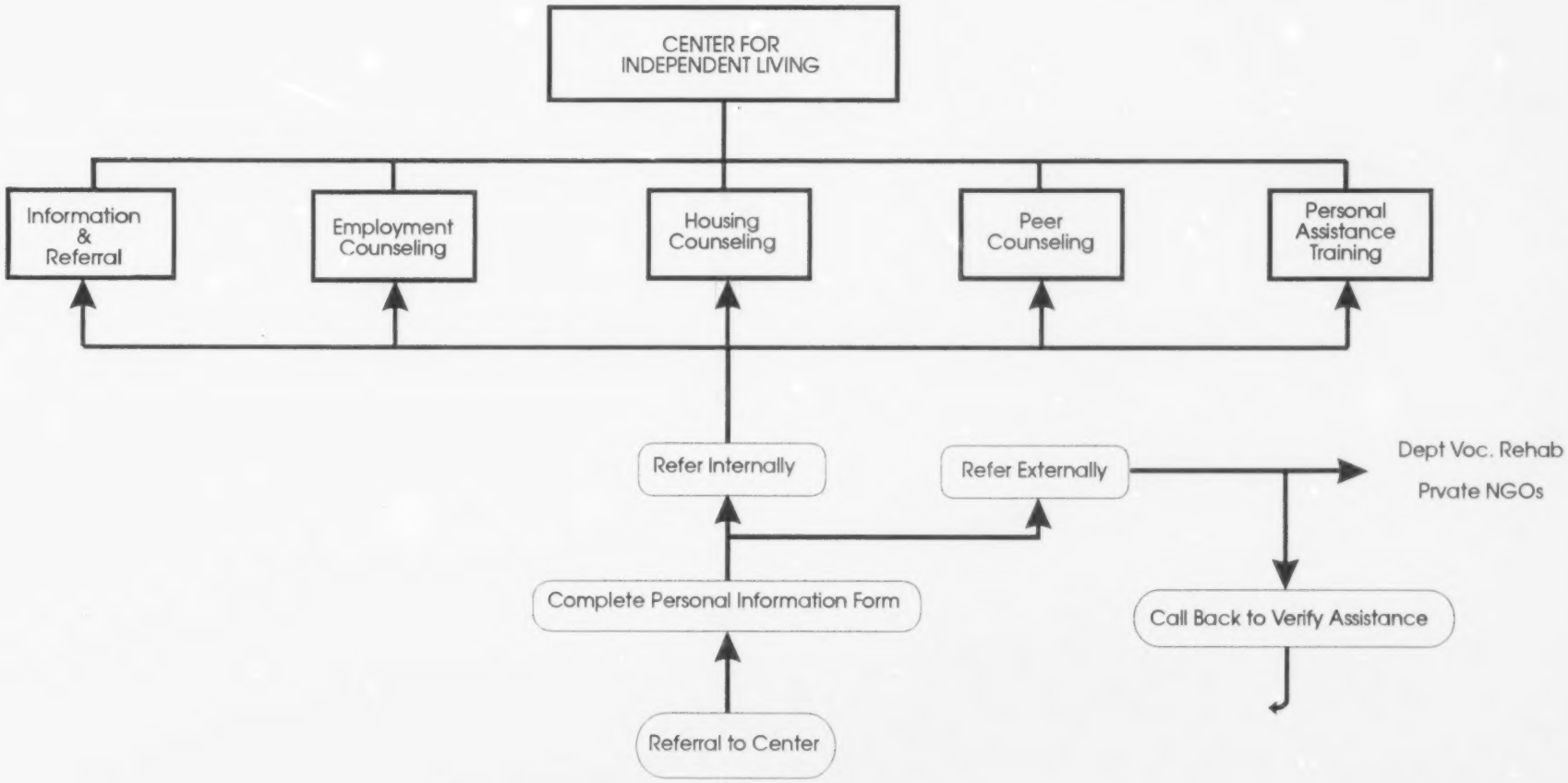

CIL OPERATING MODEL
Consumer Satisfaction
CIL Research Function
Center Services
Housing
Employment
Independent Skills Training
Personal Assistant Services
Personal Advocacy
Community Environment
Consumers
Information & Referral
Peer Counseling
Consumer progress re: independent living goals
Follow-up on all Consumers
Scan Environment for Problems
Set Priorities
System Advocacy
System Changes

Figure 1


RESOURCES
SHORT RANGE OBJECTIVES
INTERMEDIATE OBJECTIVES
LONG RANGE GOALS
Center Resources
1. Governing Board
2. Staff:
Executive Director
Peer Counsellor
I&R Coordinator
Independent Skills Coordinator
Community Advocacy Coordinator
Volunteer Staff
3. Facilities & Equipment
Information & Referral services provided
Peer Counseling provided
Personal Care Attendant services provided
Community Advocacy services provided
Training for Independent Living Skills provided
Consumers participate in and help to set CIL objectives & services
Nashville community social & economic services are fully accessible to everyone regardless of disability
Disabled in Nashville live independently to maximum extent of their capabilities
1. CIL is emulated across state
2. Disabled in Tennessee live independently to maximum extent of abilities
CENTER FOR INDEPENDENT LIVING



Functional Components of the Center for Independent Living

- The most useful comparison base for comparing results derived from the program.

Each of the services being implemented by the CIL will receive a similar design exercise to provide as much clarity in design as possible for purposes of both the evaluators and the service managers. This approach to evaluation is intended to produce both an evaluation design that is useful and a program design that is plausible, given the likely resources to be made available to the program.

CONCLUSIONS

- The evaluation of the Nashville Center for Independent Living provides that rare opportunity for effective program management which occurs when program design and evaluation begin together.

- The evaluation of personal attendant services demands an examination of assumptions about the service itself, and the development of training. The implications of a heavy reliance on training the consumer in the employment and use of an attendant raises the question of whether this is an area of training in which both consumers and agencies should examine their assumptions about the most appropriate locus of control over occupational standards in the highly sensitive area of personal assistance for persons with disabilities.

- Probably the most unusual aspect of this *discussion* of an evaluation of a training program is that the evaluation is in such an early stage of implementation. It provides a rare opportunity to explore not only the early characteristics of the evaluation but the evolution of the training itself.

  There is much to be learned from an evaluation process which begins on the same day as the program to be evaluated. Often the the thinking of the program management and other stakeholders is that evaluation involves after-the-fact determinations of whether a program "worked," "was successful," "achieved its goals." An evaluation which includes evaluability assessment and close working with the stakeholders can have much greater significance. Such an evaluation can result in clarity of purpose and in the designing of successful programs. This outcome – the designing of successful programs and being able to demonstrate this success to policy makers are key objectives of program evaluation

  This evaluation will continue over a three-year period, coinciding with the DD Council's funding of the CIL. The area of training in programs for persons with disabilities, as well as other services for persons with disabilities and many other types of services, may benefit from this evaluation and planning process. When newly funded projects plunge into their tasks, there is a strong possibility that certain decisions will never be deliberately made. Project managers are often not

free to make the carefully considered decision that an agency is simply not ready to provide a specific type of training, or that the area of training itself has many issues associated with it which must be explored. The determination at the beginning of a project of the extent to which the project's policymakers agree upon objectives and, if there is inadequate agreement, **building** agreement on the objectives, and the measures of achievement would assure strong programs, supported by the various publics necessary for their continuation, and give public programs the resources to defend themselves in the arena of competition for resources.